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ABSTRACT

Written by the parent of a moderately retarded daughter, the paper highlights helpful and disappointing events in the family's efforts to find appropriate services. After a brusque diagnosis by a doctor, early intervention support was obtained. This experience afforded factual information, emotional support, and opportunity for the child's mother to become part of a teaching team and to learn how to make existing service systems responsive. Preschool experiences included both part-day and full day programs. Elementary school enrollment was in a special private school where the child learned to read. Interaction of the father and siblings has become supportive. Other family concerns have included family respite needs, leisure programs, financial concerns, the need for related services, the child's social/sexual development, prevocational programs, achieving family balance, and the difficulties caused by family relocation (such as adjusting to a much larger school and coping with the lack of appropriate leisure time services). Interviews with other parents indicate their support for the Education for All Handicapped Children Act, and their concerns about implementation of the least restrictive environment provision, state of the art services, transition into the community, and continuation and strengthening of the law. (DB)

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The Future of Special Education: A Parent's Case Study

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A PARENT'S CASE STUDY

The Early Years

My daughter Jane was born in May of 1970. The youngest of seven children, the first year of her life was extremely difficult for all of our family. She spent most of her time fretting, crying, without a full night's sleep...always restless. Feeding her was difficult, dressing and stimulating her was a chore and fun was almost nonexistent. My recollection of that year is colored by the absence of pictures of her, negative memories reported by her siblings, a threat of child abuse by her father, and exaggerated concerns by family and friends. It was a very confusing time for me. As a mother, I kept telling myself, "My child is alright," while another voice echoed, "Jane has a serious problem."

In the first year, I asked a lot of questions about her development. Doctor shopping increased the frustration. Eventually my demands for information and help provided answers. When Jane was 14 months old, a new doctor on the scene stated, "It's simple, Mom, this child is retarded!" And so, we began the long family trek to find help for Janie. My feelings in those days were desolation, hopelessness, anger, doubt, distrust of medical personnel, and utter inability to help my own child.

Some answers came quickly...and some answers took a long time. Within 24 hours after the diagnosis, quite by chance, my husband and I met a couple who were the parents of an eight-year-old son with mental retardation. These parents were involved in programs to help families of children with disabilities. This was a landmark event. It was the most

helpful encounter in the first months after the diagnosis.

Our family, already burdened with having to assist one member deal with alcoholism, was faced with absorbing another significant stress. I had a great deal of "on the job training" with infants, but no education that prepared me to work with Jane. No one among our family and friends seemed to know what to do with her either. The diagnosing doctor recommended, "Take her home and keep her comfortable. When she is 4 years old (or thereabout) find a preschool for her." This seemed like a death sentence--were we supposed to listen to her crying for another two to three years? Six weeks later, unreferred, I walked into the Meyer Children's Rehabilitation Institute at the University of Nebraska Medical Center, a University Affiliated Facility, and asked for help.

From that day to this, Jane and I and the entire family have been receiving help. In this paper I want to highlight the events that were helpful and to describe events that were disappointing. I will begin with a description of our family and Jane's infancy. Early help to families is crucial. New families are so vulnerable after diagnosis. Only those parents that we had encountered quite by chance had relevant information. They shared their experiences in helping their son. They said that there was hope, that there were programs. They encouraged us to seek help and not to be afraid of the future.

Early Intervention

The first help came to us from a research program at Meyer's. This program was one of the early efforts funded by the Bureau for the Education of the Handicapped (BEH). This program was directed by Dr. Rune Simeonsson who was investigating the efficacy of early intervention. One of the reasons we were introduced to the program rapidly was because the project needed children under 2 years of age. Jane met the age requirement; therefore we got into the program. If that program had not been available, we would have been placed on a waiting list for an evaluation and services. At that time there was a 9-12 month delay in getting help. (Knowing the progress Jane made that first year, I do not like to think about the time we would have lost if we had not been able to begin services.) This program was a learning experience for Jane, me and all of our family. Some important changes that occurred as a result of this program were:

1. We were helped to understand Jane's disability. Factual information helped us accept her problems.

2. We gained a great deal of emotional support from Dr. Simeonsson and his staff. (One recollection is that of the nurse always holding Jane in her arms. It was very touching, because holding Jane was difficult at best. I appreciated that simple act.)

3. We learned that we could make a critical difference in Jane's life. For many months, I didn't believe that I could teach her.

4. We became a part of her teaching team. The whole family worked together to implement her programs.

5. We learned about developmental stages. The principles of normalization became a way of life. (I never knew that these principles embodied a philosophy. The dignity of risk, least restrictive environment, and age appropriateness became our watchwords.)

6. We learned about how systems did and didn't work...and how to get them to be responsive to Jane's needs.

7. We learned how to participate in planning meetings. I was in these meetings long before we knew the term I.E.P.

8. We learned how to evaluate services and programs.

Now, I don't want to mislead you. The processes decribed above took about three years. Most of the learning is still going on and at the rate we're going, it will continue to expand and grow as the years go by. This is one of the tricky points--the parents' tasks are ongoing, ever-changing and ever-challenging. The job doesn't really get done...Currently, I'm 15 years old in disability learning and experiences.

Preschool Programs

Jane participated in two preschool programs at Meyer's. The first was one hour per week. She was 2 1/2 years old at that time. Later that year, she started a two hour, five day a week program. The second program was a very structured setting with an outstanding curriculum. Fortunately, the first weeks of the program were focused on defining Jane's needs. Jane was assisted to slowly integrate into a group of ten children with various handicapping conditions. She learned many things, had good early speech intervention, and benefitted significantly from the experience. So did her mother. In two hours a mother can go to the beauty shop, grocery shop, read a book, talk to other parents, observe a class, or do nothing. What a revelation!

In 1974, due to a family crisis, I went to work as the Coordinator of the Pilot Parents Program of the Greater Omaha Association for Retarded Citizens. We moved into a new phase: I was out of the home and not able to work individually as much with Jane; I had to give myself permission to place Jane in a full day program. And eventually we learned that my working in the field benefitted Jane and the family.

After I went to work Jane was placed into the full day Coordinated Early Education Program (CEEP) of the Eastern Nebraska Office on Mental Retardation (ENCOR). CEEP was an integrated preschool/day-care program with nine nonhandicapped students and Jane. She had a resource teacher who assisted the regular preschool teacher and the day-care workers.

This was a wonderful experience. Jane's language increased dramatically.

Her social skills increased. She learned to fight, to share, to cuss, and to express her needs. She learned to interact with peers. No one had ever told me that little children are accepting. They have very few prejudices against those with differences, I learned, too.

Decision Time

The next steps weren't easy. Jane was doing well at the integrated preschool/day-care program. The public school in (1975) offered Jane a placement in a TMR class in a segregated setting. I was very concerned, and even fought with the person in charge of placement. I would not accept the placement in the TMR class. I didn't realize that I could have taken legal steps. The school personnel told me, "You really don't care about your child's education, or you would accept the placement. Don't you know that she is handicapped?" I opted to keep Jane in CEEP an additional year.

Grade School

I reviewed many alternatives before making a decision on placement. I chose a private school because the school offered the learning opportunities with realistic goals that I thought she could attain. My expectations for Jane were much higher than the public school system's assessment, and the private school agreed.

The good news was that Jane learned and succeeded. She began reading in first grade. The teacher observed that she had an outstanding memory and taught her to read by memorization. Later, phonics followed. She reads at about a 4th-5th grade level and enjoys it a great deal. She

succeeded in many areas and had a full range of educational experiences and services.

The bad news was that she was in a segregated setting. No one prepared this parent to accept segregation after Jane had successfully participated in an integrated setting for two years. This decision was most difficult for me, as I value integration. To offset this, we used every method at school and at home to broaden her integrated experiences. I don't know if the professional community realizes how difficult it is to accept segregation after you've experienced integration for your child.

Other experience during those years stand out in my mind:

Father's Interaction:

Jane's father, who was very involved in his recovery process from alcoholism, did not take an active role in her educational planning. However, he did provide excellent support to her personally. They developed a unique, supportive friendship.

Siblings' Interactions:

In the beginning Jane's siblings experienced the same reactions that her father and I initially felt. They were confused, angry, ashamed, and frightened of the future...for her and for themselves. Her brother asked, "Who wants a retarded little sister?"

Jane's brothers and sisters slowly became adjusted to the reality of her learning difficulties. They then learned that she was their little sister...and that she needed some extra help. They provided a great deal of that help, love, and support. They still do.

Family Respite Needs:

Although we had good help from her siblings and other extended family members, we needed respite services. Even though I was involved in the coordination of respite services, we didn't use them. The same fears, guilt and concerns that hamper many parents from utilization of services were present in me. Eventually, when

I figured this out, Jane had wonderful respite services. We had dependable, economic, in and out of the home services. We all benefitted from respite. Appropriate, affordable respite service has been a problem since we moved to Northern Virginia.

Leisure Programs:

Jane used many leisure time programs, mostly in segregated settings. Some programs were quite affordable, some caused a real financial drain on the family. Later, these expenses were deductible on our income tax...that helped a little.

Financial Concerns:

Covering the added expenses for a child with a handicap causes a number of difficulties. It's hard to allocate so much time, energy, and financial resources for one family member. Often one feels caught in a bind. How can you meet the needs of your child who has a handicap? Even if it means other children or the parents don't have all their needs met. To achieve a sense of balance for families in many areas takes courage and a great deal of juggling.

Related Services:

Related services are often a problem. Getting a complete evaluation with proper amounts of therapy is often a result of the parents' tenacity and insistence. Jane was able to have extensive speech and language support. She has wonderful communication

skills that are far above expectations for her I.Q. One of the most valuable resources has been that she has had the services of a movement therapist for over three years. This professional added a great deal of knowledge about Jane's condition and how to help her. It was a unique and valuable experience. The therapist was the one person who advised against modification of Jane's rocking behavior and substituted movement exercises that integrated the rocking into her total repertoire of behaviors. For the most part, this change in approach solved the problem.

Social/Sexual Development:

The growth and development of Jane's social skills, autonomy, self reliance, and self image have been an ongoing challenge. She began sex education at age 9. Each year the challenge increases as many of the supports from school and community diminish.

Pre-vocational Programs in Grade School:

Pre-vocational programs were a part of her training since she was 9 years old. Her first task was wiping off table tops after lunch. After that she learned to do a number of clean-up duties in the cafeteria.

Family Balance:

We learned how many demands would be placed on the family. Legislative advocacy became a permanent feature of our lives. Each of Jane's programs depended on public money. Our work as advocates put added stress on our family.

Trying to figure out how to balance the competing needs of each family member is a difficult task at best. Eventually we learned that Jane didn't always have to come first. Some professionals expected more involvement and commitment than we could give. A Little League ball game for her brother, a dance program for her sister, or a family vacation took precedence, and she survived.

We all learned a lot during those years.

Relocation:

The move to Northern Virginia, the result of my accepting a job with the National Information Center for Handicapped Children and Youth (NICHCY), took place in January, 1984. Had I realized the upheaval and difficulty that it was going to cause Jane, I probably would have backed out. We experienced major changes: absence of close family members, adjustment to a new neighborhood, insufficient family support services, small school versus large school differences, and many others.

Jane's behavior during these adolescent years has been difficult and has caused problems in her educational program. To get the optimal mix of discipline, positive reinforcement, educational and vocational training is a tremendous challenge for the educational system. It has been necessary for me to play a major role in advocating for her programs. Currently, she is receiving treatment support from a behavioral pediatrician. His services are making a critical difference.

Some of the experiences during these past two years have been:

School Size:

It's a lot different in a junior high school with 750 students than in a school with 65 classmates in Omaha. Jane's new high school has 1550 students, with numerous cultural and language differences.

Teachers:

Good teachers are good teachers...and we've found some super ones. Also, Jane always finds and makes friends with support staff. They have been terrific.

Labeling:

Labeling is alive and well. As a parent, I hate it. To have your child referred to as MMR is not my idea of a good idea. In high school, she is W.S., meaning Work Study, which is some better...but not a lot.

New Freedom:

Jane walked to school for the first time in her life. That was neat! (January, 1984 through April, 1985).

Least Restrictive Environment:

Our hopes for a more integrated program for Jane have not been met. During her last year in junior high, she did attend some integrated classes, such as: Home Economics, Art, Physical Education as well as integrated after school programs. However, we found in ninth grade there were no opportunities for integrated activities or classes. The teachers work hard to bring other students into the classroom, but it still doesn't provide as much integration as I think Jane should have.

Parents and Teachers:

I've enjoyed what you call the Parent/Professional Partnership because Jane's teachers and I do work together. The early interactions with Jane's teachers were very positive. They gave me the teaching tools that allowed me to help my child...this was the thing that I wanted the most.

Vocational Education:

Pre-vocational programs began in junior high. Vocational evaluation occurs in the ninth grade to plan for programs at the senior high level. There is an extensive array of programs for vocational training. We will work carefully to obtain the appropriate training. The availability of training for the world of work gives hope for independence for Jane in the future.

Physical Education:

Physical education presents concerns. The regular teacher who had Jane was totally uninformed about how to work with students with special needs. The new adaptive physical education class is for special education students and other students with needs. It never dawned on me that the nonhandicapped students would be pregnant teenage young women. I'm not prejudiced against these young women, but I do question this juxtaposition of students for service.

Leisure Time:

Leisure time and summer programs are not sufficient. Many programs are not age appropriate and are often expensive. After school programs during her ninth grade year are not really available for her, although we're working on opening more opportunities. After school programs are limited by the lack of available transportation. Jane uses a bus for special education students rather than the regular bus. We live outside the catchment area for the bus services used by the nondisabled students at her school. If she attended the local school she would be able to take "the late bus" just like other kids in the neighborhood. As it stands now, Jane must leave as soon as school ends. It is ironic that Jane has been able to use public transportation for the last four years. If the school Jane attended was in an area well served by public transportation, she would be able to stay after school and take the public bus home.

Home Life:

We have worked very hard to carry over the behavioral support that Jane receives at school into our home. She has an ironing business and does odd jobs to earn money. We've developed a support system using resources/friends' help from youthful neighbors.

Unmet Needs:

I have been working with the school to get program assistance with computers. Computer aided instruction has proven very effective in teaching Jane. This has been difficult. It doesn't seem like it should be this difficult. Also, we strive for more integration and social opportunities. Special Education teachers chaperoned football games and the school homecoming dance. We attend school plays and other programs. And Jane loves pep rallies.

In describing the details of Jane's education there are some points I need to emphasize:

1. Her growth and development, especially her emotional development, parallels that of her brothers and sisters. She certainly is more like them than different. Having raised the other children has helped me to identify her stages of development and to recognize "kid" behaviors.

2. I'm grateful that we never have had to go through a due process hearing to get her rights upheld, but we came close once. The problem was settled one step before due process.

3. Lack of integration has been the most frequently recurring problem and one that causes me considerable concern and apprehension for the future.

4. Jane's preparation for transition is extremely important. This preparation will dominate the next years of our lives. In special education, we need to do a better job in preparing young people for their social/sexual lives. We have had one bad experience in this area, even though she has had the benefit of many programs. I guess real life is more difficult to understand than experiences illustrated in textbooks.

Other Leaders Polled:

In preparing this paper, I interviewed many other parents regarding the impact of the law and their child. The responses in most cases were very similar. The parents support and appreciate the changes that have been made as a result of P.L. 94-142.

Ten years ago parents were struggling to get services in place. Integration was almost non-existent. The I.E.P. process was cumbersome and communication between parents and teachers was difficult.

Every parent discussed the progress their child had experienced during the

ten years since 94-142. One mother said, "The year following 94-142 'real integration' began." Another commented, "Our daughter has come a million miles since 94-142."

The major concerns expressed were for implementation of the Least Restrictive Environment (LRE), state-of-the-art services, and future needs. Every parent mentioned the ongoing challenge to remove barriers to total involvement for their sons and daughters. In many cases, the programs are going well. A mother of a daughter with severe retardation stated, "Today, my daughter is in an outstanding program with a maximum amount of integration and opportunities."

The parents want to keep programs on the "cutting edge" with individualization for each student. Future concerns for parents came under two headings. First, parents had concerns for the transition of their child. Parents need assistance in planning and implementing this transition process. Most of the parents want their children to be as independent as possible, living in the community. Many of these parents were fearful that the community is not prepared. The second future concern was for the continuation and strengthening of the law. Future funding is an issue that many mentioned.

I have incorporated many of the ideas of the parents in the recommendations that follow:

1. Strengthen the provision of early support for families.
2. Mandate services from birth.
3. Eliminate categorical labels.
4. Strengthen the integration mandate including provision of a "Continuum of Service."
5. Encourage stronger direction and more funding for training and retraining of personnel: regular educators, secondary as well as elementary; principals and other administrators; special educators; and people who deliver related services. It is extremely important for all involved to understand how to integrate students.
6. Promote the establishment of a national system for delivery of state-of-the-art practices.
7. Promote thorough communication training for all involved in the I.E.P. process with more attention to mediation and conflict resolution to minimize adversarial relationships.
8. Ensure that legal aid and support for parents is available so that they have equal representation without financial duress when there is a need for litigation.
9. Since many students are still in private school placement, establish a means to allow these students to participate in regular school functions to reduce the isolation of these students.
10. Recognize the need for high quality respite care.
11. Improve and implement the state-of-the-art for transition for

students after 94-142.

12. Recognize the need for mandated services for adults who need a continuum of services.
13. Increase efforts to recruit persons with disabilities to be educators and administrators in the education field.
14. Increase efforts to serve students with learning disabilities efficiently and effectively.
15. The I.E.P.: a) improve educational teaming of parents and faculty. There should be a portion of the I.E.P. for recording the home goals; b) I.E.P. meetings could be conducted in the home; c) promote coordination and communication between parents and teachers; d) emphasize student involvement when appropriate; e) encourage parents to include after school programs in the I.E.P.
16. Parents should be involved in the teaching and training of educators in inservice programs as well as pre-service programs.
17. Ensure financial stability of programs under 94-142.

Conclusion:

Many times as I gathered information for this paper, I noted gaps in the interpretation of 94-142. Let me encourage all those who serve children with special needs to interpret the spirit as well as the letter of the law. Bridge the gaps and go that extra mile to serve children. Further, as we prepare for the future let us look to the regular education system as the key to the future of integrated, normalized, age appropriate programming for children who have disabilities.

There will never, ever be enough local, state or federal funds to duplicate what the regular education program already provides...integrated, normalized, age appropriate services.